



UNIVERSITI PUTRA MALAYSIA

**UNDERSTANDING THE LEARNING EXPERIENCE AMONG FAMILY
MEMBERS OF CANCER SURVIVORS FROM A HEURISTIC
APPROACH**

TENG YAN FANG JANE

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**UNDERSTANDING THE LEARNING EXPERIENCE AMONG FAMILY
MEMBERS OF CANCER SURVIVORS FROM A HEURISTIC APPROACH**

By

TENG YAN FANG JANE

**Thesis Submitted to the School of Graduate Studies, Universiti Putra
Malaysia, in Fulfilment of the Requirements for the
Degree of Doctor Philosophy**

September 2008



DEDICATION

To

ALL FAMILIES

of

CANCER SURVIVORS

Abstract of thesis presented to the Senate of the Universiti Putra Malaysia in
fulfilment of the requirement for the degree of Doctor of Philosophy

**UNDERSTANDING THE LEARNING EXPERIENCE AMONG FAMILY
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Chairman : SHAMSUDDIN AHMAD, PhD

Faculty : Educational Studies

This study explored and provided insight into the learning experience among family members of cancer survivors. Qualitative approach specifically, Heuristic Inquiry was employed as the researcher had the direct experience in this phenomenon. She used her own 'lens' to understand her own learning experience and by sharing people's stories that have the same lived experience helped to understand as fully as possible the learning experience among family members of cancer survivors. The study was guided by five research questions: 1) What are the learning experience of the participants? 2) How do the participants learn? 3) How is learning facilitated by critical reflection? 4) How does learning lead to self-transformation? 5) What are the stages of self-transformation?

The researcher herself went through a process of internal search in which she reflected on her experience and discovered the meaning of the learning experience and developed ways to interpret them. Data were supported by ten selected participants based on the criteria: 1) The participants should be the immediate family member of a cancer survivor who has 5 years survivorship; 2) The participants should have been entrusted in providing care to the cancer survivor during the survivorship; 3) The participants have gone through self-transformation. The ten participants were interviewed in this study. The interviews were in English. Each interview lasted between an hour to about two hours, were taped recorded, transcribed verbatim and analyzed manually. Additionally, non-participant observation took place at a hospital. Besides that, the sharing with four other cancer survivors was also carried out. Ethical issues were addressed. The trustworthiness of the study was ensured through triangulation, namely member check, peer examination and a documentation of an audit trail.

The findings suggested that the understanding about their own self, others and the families of the cancer survivors at large had put them 'forefront' in dealing with the 'unknown' circumstances. The findings also revealed that family members adopted three main strategies in their learning, namely learning through reflection, learning through talking and learning through feelings. The learning was an expansion of their existing knowledge. And, it

was also found that learning is facilitated by critical reflection in three aspects. The findings also indicated that the participants went through four stages of self-transformation.

Four major conclusions were drawn from this study. First, family members, who arrive at self-acceptance and at insights of self, enhance their ability to accept their situation and find meaning in context, improve their satisfaction in life, and ultimately benefit the cancer survivors. Second, addressing issues that arise within family members reduce the stress and conflicts for everyone involved and enhance the support that family members can provide for the cancer survivors. Third, critical illness can trigger self-transformation if it is (a) incongruent to one's existing beliefs system, and (b) threatens one's assumptions and values. Finally, learning that leads to four stages of self-transformation was supported by the multiple strands of experience from the dimensions of cognitive, affective, power and actions.

This study has provided valuable information which will be beneficial to cancer stakeholders and the study has also contributed to the notion of learning and transformative learning theory.

Abstrak tesis yang dikemukakan kepada Senat Universiti Putra Malaysia
sebagai memenuhi keperluan untuk Ijazah Doktor Falsafah

**Kefahaman Terhadap Pengalaman Pembelajaran Ahli Keluarga Pesakit
Kanser Melalui Pendekatan Heuristik**

Oleh

TENG YAN FANG JANE

September 2008

Pengerusi : SHAMSUDDIN AHMAD, PhD

Fakulti : Pengajian Pendidikan

Kajian ini bertujuan mendalami kefahaman terhadap pengalaman pembelajaran ahli-ahli keluarga pesakit kanser. Rekabentuk kajian kualitatif menggunakan kaedah “Heuristic Inquiry” telah digunapakai dalam penyelidikan fenomena ini. Kajian ini berpandukan kepada soalan-soalan berikut: (1) Apa pengalaman pembelajaran ahli-ahli keluarga pesakit kanser? 2) Bagaimana mereka belajar? 3) Bagaimana refleksi secara kritikal membantu pembelajaran mereka? 4) Bagaimana refleksi secara kritikal dalam sifat transformasi mereka? 5) Apakah tahap-tahap transformasi mereka?

Kaedah “Heuristic Inquiry” memerlukan pengalaman secara langsung penyelidik sendiri dan disokong oleh responden lain. Seramai sepuluh responden yang dikenalpasti telah ditemubual. Responden telah dipilih

berdasarkan kriteria berikut: i) merupakan ahli keluarga terdekat bagi pesakit kanser; ii) pesakit kanser telah mengalami kanser sekurang-kurangnya lima tahun; iii) ahli keluarga berkenaan mengalami transformasi melalui pengalaman tersebut.

Teknik pengutipan utama data dalam kajian ini adalah satu siri refleksi penyelidik sendiri dan disokong oleh sepuluh responden lain melalui temubual berpanduan kepada garis panduan yang telah direkacipta. Permerhatian juga telah dibuat di wad kanser di sebuah hospital selama enam bulan dan temubual terhadap empat pesakit kanser lain secara individu juga telah dilakukan. Temubual telah dijalankan dalam Bahasa Inggeris dan ianya telah dirakamkan dan kemudian ditanskrip verbatim. Analisis data adalah manual dengan menggunakan perbandingan sekat telah berjaya menghasilkan tema-tema berkaitan. Isu etika telah diambil kira. Untuk tujuan kesahihan kajian, teknik pemeriksaan rakan, triangulasi dan semakan ahli telah digunakan.

Dapatan kajian mencadangkan responden lebih mengenali diri dari pengalaman pembelajaran tersebut telah meletakkan mereka di situasi sebenar untuk mengatasi pelbagai cabaran. Responden juga telah mengambil kira refleksi, perbincangan dan perasaan semasa belajar dari pengalaman pembelajaran itu. Pembelajaran tersebut merupakan pengembangan pengetahuan sedia ada mereka. Selain daripada itu, dapatan

kajian juga membuktikan refleksi membantu secara langsung dalam pembelajaran pengalaman. Seterusnya, dapatan kajian juga mencadangkan responden mengalami transformasi dalam empat tahap.

Empat kesimpulan telah dirumus dari kajian ini. Pertama, kefahaman sendiri yang lebih utuh telah membantu seseorang menerima keadaan sehingga dia menerajui hidup dengan lebih berkesan di mana akhirnya memafaatkan pesakit kanser. Kedua, mendalami isu di kalangan ahli keluarga pesakit kanser telah mengurangkan tekanan dan konflik di kalangan keluarga pesakit kanser. Ketiga, transformasi didorong sekira (a) ianya bercanggahan dengan pegangan dan nilai yang sedia ada; (b) ianya menggugat tanggapan atau sistem nilai. Akhirnya, transformasi yang timbul daripada pengalaman pembelajaran berlaku dalam empat tahap disokong oleh pelbagai dimensi pengalaman iaitu kognitif, afektif, kuasa dan tindakan.

Kajian ini telah menyumbang informasi yang bernilai untuk stakeholder kanser dan sumbangan kajian kepada teori pembelajaran dan teori pembelajaran transformatif telah juga direkodkan.

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If ever a dissertation was more a process than a product, then this must be it. And throughout the process many people contributed, in many meaningful ways, to bringing the final product into being. So many, in fact, that I cannot begin to name them all. Yet, some people were especially important in this project—coming to my aid at critical moments in the process—and therefore I would like for them to know how thankful I am for their involvement.

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APPROVAL

I certified that an Examination Committee met on 4 September 2008 to conduct the final examination of Teng Yan Fang Jane on her Doctor of Philosophy thesis entitled "Understanding the Learning Experience among Family Members of Cancer Survivors from a Heuristic Approach" in accordance with Universiti Pertanian Malaysia (Higher Degree) Act 1980 and Universiti Pertanian Malaysia (Higher Degree) Regulations 1981. The Committee recommends that the student be awarded the degree of Doctor Philosophy.

Members of the Examination Committee were as follows.

Bahaman Abu Samad, PhD

Associate Professor
Institute of Social Science Studies
Universiti Putra Malaysia
(Chairman)

Maimunah Ismail, PhD


Professor
Faculty of Educational Studies
Universiti Putra Malaysia
(Internal Examiner)

Rahim Md Sail, PhD

Professor
Faculty of Educational Studies
Universiti Putra Malaysia
(Internal Examiner)

Rosemary S. Caffarella, PhD

Professor
Department of Education
University of Cornell
(External Examiner)



HASANAH MOHD. GHAZAL, PhD
Professor and Deputy Dean
School of Graduate Studies
Universiti Putra Malaysia

Date : 23 October 2008

This thesis was submitted to the Senate of the Universiti Putra Malaysia and has been accepted as fulfilment of the requirement for the degree of Doctor Philosophy. The members of the Supervisory Committee were as follows:

Shamsuddin Ahmad, PhD

Senior Lecturer
Faculty of Educational Studies
Universiti Putra Malaysia
(Chairman)

Azimi Hamzah, PhD

Professor
Faculty of Educational Studies
Universiti Putra Malaysia
(Member)

Azahari Ismail, PhD

Associate Professor
Faculty of Educational Studies
Universiti Putra Malaysia
(Member)



AINI IDARIS, PhD

Professor and Dean
School of Graduate Studies
Universiti Putra Malaysia

Date: 13 November 2008

DECLARATION

I declare that the thesis is my original work except for quotations and citations which have been duly acknowledged. I also declare that it has not been previously, or is not concurrently, submitted for any other degree at Universiti Putra Malaysia or other institution.



TENG YAN FANG JANE

Date: 15 September 2008

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LIST OF ABBREVIATIONS

ALL	Acute Lymphoblastic Leukemia
AML	Acute Myeloid Leukemia
CLL	Chronic Lymphocytic Leukemia
CML	Chronic Myeloid Leukemia
IONS	Institute of Noetic Society
LSSC	Loren Smith Cancer Center
NCCS	National Coalition of Cancer Survivorship
NSP	Nasopharyngeal Carcinoma Cancer

CHAPTER 1

INTRODUCTION

As I remembered, I was jumbled with a concoction of feelings and confusions during the time my mother was stricken with cancer. Since then, I have consciously thought and reflected on my experience and learning which had impacted my life. At the same time, I have seen how others journeyed through and discovered about people started to transform. While in this chaotic and confused situation, my sense of curiosity and fascination, along with my desire for understanding this experience, was immediately piqued when I listened to many cancer survivors' stories where they credited their family members for the support. And I personally believed, "If I can properly listen to the pain of my family members, perhaps I can hear more clearly the suffering of the entire cancer survivors' community". Thus, the need to deepen my understanding of learning and people's transformation has become a real concern and this became the first step in my endeavor.

Background of the Study

Although cancer has "come out of the closet," much of what we read in newspaper and magazines is about the disease itself or its probable causes or new methods of treatment. There is a little information about how family

members deal with cancer on a day-to-day basis. When one member of a family is diagnosed with cancer, it affects every one in the family. Many a times family members feel helpless as they accompany the cancer patients through the rigors of diagnosis and treatment. The roles of the family member are a complicated one. Although family members would have no choice other than to care for their cancer survivors, the on-going stress of coping can drain them physically, emotion/ally, and spiritually.

Notable here is that cancer is a blow to every family it touches, and family members who take the roles of 'caregivers' have generally gone through lots of experience and learning. Coping with illness with the survivors is a tremendous healthcare responsibility for generally untrained family members. Family members may find it difficult to cope, and feel great concern over side effects and pain management. Family members often have to put their life on hold, and spend enormous amount of time tending to their cancer survivors. Often they work with no resources or support, and at time goes on, one can become susceptible to illness themselves. Furthermore, family members of cancer patients change their lives to make way for their loved ones and seek ways to beat the disease, forfeiting work and social functions to attend medical appointments, and in particular, care for their loved ones. Therefore, these family members' probably need as much as attention as the patients. If family members' needs for information and psychological assistance are